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Long covid and disability: a brave new world

Nicholas Evans and colleagues argue that long covid needs to be better recognised, understood, and supported, and should stimulate a rethink of our approach to disability

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One billion people worldwide live with a disability,¹ but they are often overlooked in discussions of pandemic preparedness and response.^{2,3} People with physical and cognitive disabilities—including those with “invisible” disabilities that are not obvious from the outside—were at disproportionate risk of harm from covid-19 because of their pre-existing medical conditions or their social circumstances.^{4–6} People in the UK whose disabilities affected their day-to-day function were up to three times more likely to have died from covid-19.⁷ They also experienced disproportionate loss of access to medical services, education, employment, and care.⁸

The number of people experiencing disability is being swelled by people with “long covid,” in which symptoms persist after the acute viral infection subsides. The term “long covid” was coined by patients, initially being used on social media to describe symptoms that were impairing quality of life.⁹ We argue that this experience generates an obligation to recognise long covid as a potentially disabling condition defined by clinical diagnostic criteria and supported by ongoing clinical research. Such recognition would also re-enforce the obligation of the state to extend and expand supportive infrastructure and policy for people with other disabilities. The need for just social policies grounded in contemporary theories of disability, designed by disabled people for disabled people, can also form the basis for advocacy and policy change beyond the pandemic.

What is long covid?

Although long covid is widely acknowledged to exist, diagnostic criteria vary, with different authorities acknowledging a diversity of symptoms and severity levels. Symptoms include fatigue, cognitive symptoms such as difficulty concentrating and impaired memory, and sensory changes like permanent loss of smell or taste.¹⁰ Physiologically, long covid may cause damage to extremities, in some cases requiring amputation^{11,12}; multiorgan injury such as chronic kidney disease requiring dialysis or transplant^{13,14}; or respiratory complications and persistent post-exertional symptoms. These symptoms may exist in isolation or in clusters, and though they range in severity, many greatly affect people’s wellbeing and life plans.

The exact prevalence of long covid is unknown because the wide range of presentations overlap numerous other conditions, there is no definitive diagnostic test, some people with long covid may struggle to access care (and thereby be counted), and covid-19 testing was difficult to access in many settings at the beginning of the pandemic. In the UK,

the Coronavirus Infection Survey conducted from April 2020 to August 2021 estimated between 3% and 11% of 15 061 participants with covid-19 infection experienced symptoms for more than 12 weeks.¹⁵ The US Centers for Disease Control and Prevention found up to 20% of 353 000 patients aged 18–64 years had one symptom attributable to covid-19 more than four weeks after infection.¹⁶ At its lower bound, at least 16.5 million of the 562 million people infected with covid-19 worldwide as of 20 July 2022¹⁷ may have long covid, but at its higher estimates, the number could extend to over 100 million people.

Symptoms of long covid can persist for over a year and potentially be permanent. One international online survey in 2020 of 3762 people in 56 countries with confirmed or suspected covid-19 who had illness lasting over 28 days found 45% of respondents had required a reduced work schedule, and another 23% had left the workforce because of suspected long covid.¹⁸ Long covid in children and young people could similarly jeopardise educational attainment.

Long covid and disability

Long covid itself may not be a disability but given its potentially debilitating effects on people’s lives, it can be disabling. Long covid symptoms may also constitute disabilities because of loss of human function or because of a persistent impairment that undermines a person’s quality of life.¹⁹

Another way in which long covid symptoms may be disabling is if a person experiences social discrimination or social subordination, wherein they lose status in society as a result of perceived “defective bodily functioning.”^{19,20} Some evidence suggests that people with long covid already experience discrimination. For example, in a cross sectional survey of 127 patients with long covid symptoms conducted between August 2020 and March 2021 in Japan, 55 people had experienced at least one form of discrimination and stigma, including being treated as if still contagious or being the subject of harmful rumours or verbal harassment.²¹ Subsequent research does not suggest attitudes have changed.²² People with long covid can also experience social isolation, stigma, and loss of social identity because of their inability to perform at work, maintain their relationships, care for their families, exercise, and so on.²³

Clear diagnostic criteria facilitate care and legal recognition

Long covid would be better understood as a potentially disabling condition if there were clinical diagnostic criteria to create meaningful pathways to

care. This would benefit people with disabling symptoms in at least three ways. Firstly, those affected may need ongoing medical and allied care to retain or restore functions or to fulfil their life plans. Applications for state funded disability related health assistance usually require a clinical examination and sometimes a diagnostic code, such as an ICD-10 code. Diagnostic criteria for long covid may facilitate access to interventions and services that support social engagement and physical function (eg, hand rails, modified work environments, or access to rehabilitative therapy or psychiatric care).

Clear diagnostic criteria—supported by ongoing research into the underlying mechanisms of persistent symptoms²⁴—might also reduce uncertainty and validate the experience of patients with long covid, including those who did not have access to testing at the time of presumed infection. A 2020 qualitative study in 24 patients with long covid identified uncertainty and being taken seriously as important concerns.²⁵

The third and potentially more profound implication of establishing diagnostic criteria for long covid is in legal recognition of disability through instruments such as the Americans with Disabilities Act in the US and the Equality Act 2010 in the UK. Because people with long covid may experience long term, substantial impairment of their ability or autonomy to participate in society, in principle these instruments may already cover long covid. For example, the Equality Act covers discrimination on the grounds of “protected characteristics,” one of which is disability, and can require employers and others to make “reasonable adjustments” for people with disabilities. However, the widely variable presentations of long covid and absence of definitive diagnostic criteria or biomarkers may make it harder for patients to prove that they qualify as disabled. The Americans with Disabilities Act Amendments Act also requires people to prove qualification before they can claim a right to accommodations.²⁶ This means that the disability must be recognised by a court rather than relying on self-reported limitations in a person’s ability to undertake major life activities.

Conversely, formally conceiving of long covid as a disability in law or policy is not the same as an individual determining whether their identity has changed to include “disabled.” This creates a tension between self-identification as disabled and the law, where it is often necessary to have clear definitions and boundaries. Excessive focus on biomarkers or black and white diagnostic criteria for long covid could inadvertently exclude people who experience debilitating symptoms that do not fit accepted definitions of disease.²⁷ Disability is not merely a medical phenomenon but a social one, and a loss of social function should be included as part of an assessment of disability.

Given the strong grassroots and patient led movement to recognise long covid, patients and advocacy groups should be included in developing disease criteria as a basis for self-identification.²⁸ The successes of disability rights movements and other movements such as HIV/AIDS activism, in which self-advocacy formed the basis for change are instructive: nothing about us, without us.²⁹ Establishing well defined criteria can empower people with long covid by providing a long term basis for coalitions and building communities. These can be leveraged into activism and political action to bring about social change, including by organising to motivate state responses to long covid.

State obligations

Diagnostic criteria can provide the basis for care and accommodations, but it is the state that is required to meet the needs of people with disabilities through medical care or other political,

infrastructural, or welfare systems. In the case of long covid, these needs may be diverse. People with organ injury will require continued and robust access to affordable and accessible healthcare. Those whose symptoms impair mobility may require aids or modifications to their physical environments, like many other people with physical disabilities. People with cognitive deficits, profound fatigue, or psychiatric symptoms may require specific support—for example, access to unemployment or other benefits, modifications to their work duties or schedule, or allowances for remote working when symptoms preclude commuting.³⁰ Flexible attendance and modified activities for students with brain fog and other stress mediated effects of long covid may be necessary to support educational attainment.³¹ Increases in funding for, training, and availability of home care aides for families will arguably be needed when care givers and primary earners are affected by long covid.

Many of these accommodations and improvements will arguably be best financed or accomplished through state intervention and may require policy interventions. For example, private firms may decide against the perceived additional expense of accessibility unless it is considered “reasonable” and enforceable by legal protections such as the Equality Act in the UK. Given the potential scale of long covid, novel workplace legislation mandating the right to remote work and flexible work hours (for long covid as well as other important needs such as other disabilities, family illness, and childrearing) would improve accessibility. There may even be grounds to invert the status quo on accessibility and make the right to flexible work a presumption, effectively placing the onus on employers to justify on-site work requirements. For people whose symptoms flare or require additional medical leave, legislation introducing formal paid time off legislation in countries that do not have it would be a step towards an equitable society built on the recognition of disability.

In other cases, accommodation may simply be a public good. Historically, mobility aids such as dropped kerbs in pavements allowing access to the road and ramps into or through buildings rather than stairs benefit people with a variety of mobility needs—some, but not all, resulting from disability.³² These public works are typically achievable at scale only with state support and also benefit the broader population.

These accommodations are social needs that predated the pandemic but are now critical with the rise of long covid. Crucially, support services are currently understaffed and under-resourced. The covid-19 pandemic has seen the degradation or collapse of welfare services, combined in some countries with decades of defunding and neglect.³³ These services now have millions of new users.

Recognition, respect, access to care, and an adjustment of our social norms and infrastructure have long been demands of disability activists. Covid-19, as in many other areas of life, may have shown the depth of our failures, but it did not create them. The emergence of long covid has made visible an emerging disability community that has the potential to shine a light on disability rights. What is now needed is a concerted political will to act to benefit the millions of individuals who are, or will become, disabled as a result of this global pandemic.

Key messages

- The rise of long covid has created millions of new people with disabilities who will have to navigate the post-pandemic world
- The need for change to support people with disabilities predated the pandemic

- Long covid needs to be legally recognised as disabling through clinical research and practice
- The state must support people with long covid through expanded or reformed infrastructure and policy and by changing social norms
- Such changes will benefit all disabled people and wider society

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